Discover Psychology

RESEARCH Open Access

Exploring the psychosocial impact of having a child with spina bifida

Katie O'Connor[1*] and David Hevey[1]

*Correspondence:
Katie O'Connor
oconnk52@tcd.ie
[1]School of Psychology, Faculty of Arts, Humanities and Social Sciences, Trinity College Dublin, Dublin City University, College Green, Dublin 2, Ireland

Abstract

Parents of children with physical disabilities such as spina bifida (SB) are faced with a series of long-term difficulties, placing considerable strain on both psychological and social resources. Although there is a small amount of quantitative literature pertaining to the psychosocial impact of having a child with SB, there is a lack of qualitative studies assessing the impacts of caring for a child with SB. Thus, this study sought to qualitatively explore the psychosocial impact of having a child with SB. We aimed to understand what are the psychosocial impacts associated with having a child with SB, how are such individuals supported, and what recommendations do these parents have to better support parents of children with SB. A qualitative cross-sectional design was implemented with semi-structured online interviews. 12 participants were recruited using purposive sampling and interviews were audio-recorded, transcribed, and analysed using thematic analysis. We identified five themes relating to the psychosocial impact of having a child with SB: balancing daily life demands, social challenges and relationship changes, emotional impact, benefits of social support networks and inadequacy of psychological supports for parents. The findings underscore the critical need for the improvement of psychological support services tailored for parents of children with SB.

Highlights

- Qualitatively explored the psychosocial impacts of caring for a child with SB amongst Irish parents.
- Identified five themes relating to the psychosocial impact of having a child with SB: balancing daily life demands, social challenges and relationship changes, emotional impact, benefits of social support networks and inadequacy of psychological supports for parents.
- Findings of the study highlight the need for targeted interventions to support the unique psychosocial needs of parents of children with SB.

Keywords Spina bifida, Neural tube defects, Psychosocial impact, Disability, Qualitative study

© The Author(s) 2025. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://creativecommons.org/licenses/by-nc-nd/4.0/.

1 Introduction

Neural tube defects (NTDs) comprise the second most common congenital birth defect worldwide, caused by defective closure of the neural tube, leading to infant death or lifelong disabilities [45]. To date, the prevalence and associated adverse outcomes of NTDs are disproportionately high in developing countries, despite the general recommendation of periconceptional folate acid supplementation [33]. Historically, Ireland has been associated with high incidences of NTDs, with an overall rate of 1.05 per 1000 births, in comparison to 0.36 per 1000 in Europe [46, 47] and 0.46 per 1000 in both Canada and Western Australia [31].

Although the term NTDs encompasses a range of birth defects, anencephaly and spina bifida (SB) account for the majority of all NTDs [12]. SB ("split spine") is the most prevalent form of NTD, affecting approximately 1300 babies in the United States each year [69]. It is characterised by an incomplete closure of the neural tube during the first trimester of pregnancy, leading to neurological dysfunction below the lesion level [52].

1.1 Forms of spina bifida

There are three forms of SB depending on the severity of the condition: SB occulta, meningocele and myelomeningocele [9]. SB occulta is the mildest form of SB [20], characterised by a small defect in one or more of the vertebrae that make up the spine, however, the site of the lesion is closed [54]. Research has largely considered SB occulta as a benign entity without significant clinical consequences as many patients are asymptomatic [57] and experience minimal neurological or developmental impairments [63].

Meningocele is the rarest form of SB and is characterised by the bulging of the meninges of the spinal cord through an opening in the vertebrae, resulting in a fluid-filled sac, or cyst, protruding from the back [20]. The cyst, which can vary in size, is routinely surgically removed within 48hr after birth, allowing for normal development [70]. Thus, although this form of SB may cause minor disabilities and neurological sequelae, there is typically minimal nerve or spinal cord damage [15].

Myelomeningocele, accounting for over 75% of all cases, is the most serious form of SB, and occurs when the sac protruding from the infant's back contains the spinal cord and nerve tissues [70]. As there is no skin covering the malformation, the spinal cord is exposed to amniotic fluid that has open communication with the external environment [20]. Postnatal treatment of myelomeningocele occurs within 48hr of birth in order to enclose the spinal cord and the damaged nerves surrounding the malformation [22]. Myelomeningocele typically presents at the lumbar and sacral level and is associated with multiple malformations of the brain [73]. Impairments may be presented in various degrees of morbidity including hydrocephalus [11], lower limb weakness or paralysis [62], bladder/bowel dysfunction [71], and attention, memory and executive function deficits [61, 76]. These complex and diverse lifelong complications have lasting physical, neurological and psychosocial consequences, and individuals with SB require ongoing treatment and monitoring throughout their lifetime [70].

1.2 Psychosocial impact on parents of children with physical disabilities

The impact of such disabilities extends beyond the individual. Parents are also faced with a series of long-term difficulties, placing considerable strain on both psychological and

social (psychosocial) resources [78]. As there is no specific definition of 'psychosocial impact' to date [72], for the purpose of this study we have defined 'psychosocial impact' as a combination of psychological, emotional, social, financial and occupational factors that directly affect parents of children with a physical disability, including caregiver burden.

1.2.1 Caregiver burden

In terms of the psychosocial impact of having a child with a physical disability, evidence suggests that increased caregiving demands experienced by these parents may at times seem overwhelming as they face a variety of complex responsibilities and challenges [25, 55]. Apart from the typical carer responsibilities associated with child rearing, parents of children with physical disabilities must also cope with additional disability-related responsibilities, such as the management of a child's medical regimen [23]. These parents are often faced with sudden and significant life events such as high-risk surgeries, in addition to the continuous daily demands of having a child with a disability [75]. They are also required to cope with new medical information, adjustments to their daily routines, and important decision-making regarding the medical, social, and educational needs of their child [52].

1.2.2 Psychological impacts

In terms of the psychological impact of caring for a child with a physical disability, extensive research has found that compared to parents of typically developing children, these caregivers experience greater levels of psychological distress, including anxiety and depression (e.g., [3, 19]). Additionally, studies have reported that these parents experience higher levels of parental stress in comparison to parents of able-bodied children [2, 16, 55]. In particular, parental stress in this population has been associated with concerns around the child's negative prognosis, and the uncertainty and unpredictability regarding the course of the child's condition [41, 68].

1.2.3 Social impacts and relationships

Parents of children with physical disabilities may also adjust their social and family life to accommodate their child, as caring for a child with a disability can be a significant responsibility and increases the complexity of the parent's role. Research has found that approximately one quarter of parents of children with disabilities have reported that the caring role negatively impacted their social life, with roughly 31% of parents reporting that they had completely lost contact with friends, relatives, or their extended family [28]. Parents have also reported a lack of understanding by relatives and other community members of their difficulties, and little or no acknowledgement of the challenges they face (e.g., [2]).

Caring for a child with a physical disability may also strain family relationships, as caregiving commitments may result in parents having limited opportunities to spend time alone together [66]. Indeed, lower couple satisfaction has been reported among parents of children with disabilities, compared to that of parents of children without disabilities [64]. However, some studies have reported that parents' relationships were strengthened as a result of their child's disability due to their mutual commitment to

meeting their child's needs, and acknowledging the care burdens placed on the child's main carer [66].

1.2.4 Occupational and financial impacts

Caring for a child with a physical disability is often associated with illness- or disability-related dilution of familial resources, such as financial burden [23]. Indeed, there may be financial pressure placed on the entire family due to increased expenses and decreased income. Both medical and nonmedical expenses, as well as challenges in accessing government support, are major contributors to the financial stress faced by these families [38, 42]. Additionally, as priority is often placed on the child's care, parents of children with physical disabilities may not be able to sustain their employment [38]. Consequently, parents experience financial and social instability, in addition to physical and psychological distress [48].

1.3 Psychosocial impact of having a child with spina bifida

As parents undertake complex care tasks while balancing all other facets of family life and work obligations, the complexity of the parental role and the subsequent wellbeing of these caregivers is progressively becoming a public health concern [25, 66]. In recent years, extensive research has identified the psychosocial impact of having a child with a chronic health condition in several populations, including parents of children with cerebral palsy [2] and cardiovascular disease [32]. However, a more comprehensive understanding of the implications of caring for a child with complex care requirements in today's modern family is vital, given that increased caregiving demands pose a significant risk for adverse psychosocial effects [25, 77].

To date, there is little reported on the psychosocial impact of having a child with SB, despite the number of infants born with this NTD each year. Caring for a child with a NTD means coming to terms with the condition, its associated complications, and the subsequent effect on family and friends [60]. Whilst there is substantial evidence in the literature highlighting the impact on individuals living with SB (e.g., [5, 58]), the impact on caregivers is less well documented.

Although the literature is limited, studies have identified that parents of children with SB experience higher levels of psychological strain than parents of able-bodied or typically developing children (e.g., [30]). Furthermore, it has been reported that parents of children with SB experience elevated feelings of social isolation [75], economic hardship [74], and low levels of perceived parental competence [30]. Thus, these findings suggest that SB presents a multitude of challenges to parents, which must be addressed to mitigate the considerable burden that SB places on caregivers.

1.4 The current study

Much of the research exploring the impact of having a child with SB is limited to quantitative research (e.g., [36, 75]). Thus, while there is a small amount of quantitative literature pertaining to the psychosocial impact of having a child with SB, there is a lack of literature qualitatively assessing the subjective experiences of parents of children with SB, as illustrated by Rofail et al. [60].

To the best of our knowledge, this is the first study that qualitatively explores the psychosocial impact of having a child with SB. A significant benefit of qualitative research is

that it is primarily inductive and explorative in its procedures, and therefore, suitable for situations where impacts need to be investigated [56]. We aimed to understand: (i) what are the psychosocial impacts associated with having a child with SB, (ii) how are such individuals supported, and (iii) what recommendations do these parents have to better support parents of children with SB?

2 Method

2.1 Design

We utilised a cross-sectional qualitative approach as it is primarily inductive and explorative in its procedures; consequently, it is suitable for situations where impacts need to be investigated [56]. The cross-sectional approach was implemented by conducting interviews within a 4-month period and subsequent analysis across a 2-month period. Interviews were favored over focus groups as participants are more likely to raise socially sensitive topics in interviews [34].

2.2 Participants

Participants were recruited to partake in semi-structured interviews designed to capture the experiences of parents who have a child with SB. Purposive sampling was utilised to reach this specific group, whereby we attempted to ensure that participants represented a mix of gender, age, and children with various forms of SB. Participants were also recruited based on a set of inclusion and exclusion criteria. The inclusion criteria for participants were as follows: (1) They were over the age of 18, (2) they resided in Ireland and (3) they were a parent or primary caregiver of a child with SB, aged birth to 21 years. The exclusion criteria were (1) parents or caregivers under the age of 18, (2) parents or caregivers who had a deceased child with SB and (3) parents or caregivers who had a child with SB over the age of 21.

For the purpose of this study, SB organisations were defined as organisations with a primary focus on providing services, supports, and advocacy for individuals with SB and their families. Two SB organisations in Ireland were identified by conducting a comprehensive search of healthcare databases and online resources to identify known organisations. The researcher sent an email to both organisations in the Republic of Ireland and Northern Ireland, including Spina Bifida and Hydrocephalus Ireland and SHINE (Spina Bifida, Hydrocephalus, Information, Networking, and Equality Northern Ireland Services). This email contained the recruitment notice and contact details for the researcher. Both organisations shared the notice across their channels. Similarly, the researcher sent an email to online SB parent groups, consisting of online communities of Irish parents on Facebook, who shared the notice with their members. These parent groups were identified through online platforms and by consulting support organisations. The researcher also supplemented this recruitment strategy with advertisements on LinkedIn and Twitter, in order to engage with communities that may have been interested in taking part. Social media recruitment assists researchers in accessing groups and individuals that may be hard to reach [39].

2.3 Data collection

The time, location, and mode of interview (virtual, telephone or in-person) were chosen by the participant. All participants opted to carry out the interviews using Zoom,

a remote video conference application. The average length of interview was 39 min and interviews spanned from 19 min to 1hr and 6 min. Participants signed an online consent form in advance of the Zoom interview and returned it via email.

The interview was conducted through a semi-structured format, where the researcher asked participants the impact of their child's diagnosis of SB on areas of parenting, work, finances, relationships, and psychological and emotional functioning. Participants were also asked about the supports they receive, their view on supports available and their recommendations to better support parents of children with SB (Sample interview questions are presented in Table 1). These semi-structured interview questions were designed by the first author by utilising previous studies exploring the psychosocial impact of caring for a child with a chronic illness or disability (e.g., [18, 50, 79]), and were reviewed by the second author, given his extensive experience in health psychology research. The interview questions were intentionally broad and open-ended, providing parents with scope to discuss topics not routinely explored in quantitative assessments. Additionally, participants were provided with an opportunity to raise issues pertaining to other domains and issues as they felt appropriate. This approach allowed for rich data to be collected that provided insight into the unique experience of each participant.

The interviews were audio-recorded via Zoom and the subsequent pseudo-anonymised transcripts were stored on a secure, password protected laptop. Transcription of the interviews was performed by the researcher. This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Psychology Research Ethics Committee (REC), Trinity College Dublin (SPREC012024-18).

2.4 Data analysis

Braun and Clarke's [7] thematic analysis was used to determine the themes emerging from the qualitative transcripts. Thematic analysis is effective as it allows the researcher to form relationships between issues and topics that emerge from the data [7]. In the present study, one researcher was primarily responsible for data analysis. This form of thematic analysis required the researcher to (1) familiarise themselves with the data, (2) generate initial codes, (3) search for themes, (4) review themes, (5) refine themes and (6) produce the report. During the transcription process, over 7hr of audio were transcribed, and any information that made participants potentially identifiable was omitted from the transcripts. Subsequently, the initial process of descriptive coding was undertaken and followed by a process of "coding the codes", where codes became more interpretive with the aim of linking together and converging various codes. The transcripts were coded using Microsoft Word. Following this, themes were extracted, defined, and refined. Quotations from participants were utilised to illustrate themes.

Table 1 Sample interview questions

Sample interview questions
Has having a child with SB affected you as a family/your relationship with other family members?
How did you first hear about the diagnosis, and how did it make you feel initially?
Has your child's condition had a positive impact on you and your family?
Can you tell me about how you felt during the course of any treatment/surgical intervention your child may have had in the past or in the present?
Can you tell me has having a child with SB impacted your career in any way?

Table 2 Parent and child descriptives (N = 12)

Parental factors			Child factors		
Interview	**Name**	**Relationship to child**	**Child's gender**	**Form of SB**	**Age of child**
1	Sarah	Mother	Male	Myelomeningocele	11
2	Kate	Mother	Male	Myelomeningocele	8
3	Nicole	Mother	Female	Myelomeningocele	2
4	Jessica	Mother	Male	Myelomeningocele	7
5	Monica	Mother	Male	Myelomeningocele	15
6	Olivia	Mother	Female	Myelomeningocele	16
7	Ellen	Mother	Male	Myelomeningocele	19
8	Louise	Mother	Female	Myelomeningocele	5
9	Amelia	Mother	Female	Myelomeningocele	2
10	Patricia	Mother	Female	Myelomeningocele	15
11	Cara	Mother	Female	Myelomeningocele	3
12	Rachel	Mother	Female	Myelomeningocele	8

IDs provided are pseudonyms

Table 3 Qualitative themes and subthemes identified

Themes	Subthemes
Balancing daily life demands	• Managing work, the household and the child's medical needs • Financial burden • Changes in employment
Social challenges and relationship changes	• Lack of understanding from others • Impact on relationships with partner and other children • Impact of accessibility barriers on family life
Emotional impact	• Emotional responses to the diagnosis • Navigating the unknown • Transformative insights
Benefits of social support networks	• Practical and emotional support from family and friends • Importance of connecting with other families with children with SB
Inadequacy of psychological supports for parents	• Unmet psychological support needs • Avenues for improvement

3 Results

This sample consisted of 12 mothers of children with SB who resided in Ireland. Previous research has recommended that qualitative studies require a minimum sample size of at least 12 to reach data saturation [14, 24]. Therefore, a sample of 12 was deemed sufficient for the scale of this study. The children ranged in age from 2 to 19 years. The majority of the children had a primary diagnosis of myelomeningocele, however, the specific form has been removed to protect confidentiality. Detailed sample demographics are presented in Table 2. Participants have been given pseudonyms in order to protect confidentiality and anonymity.

We identified five major themes related to the psychosocial impact of having a child with SB, including balancing daily life demands, social challenges and relationship changes, emotional impact, benefits of social support networks and inadequacy of psychological supports for parents (see Table 3). The first three themes, balancing daily life demands, social challenges and relationship changes, and emotional impact, address research question (i), by highlighting the psychosocial impacts experienced by parents of children with SB. The remaining two themes, benefits of social support networks and inadequacy of psychological supports for parents, address research questions (ii) and (iii), by highlighting the various supports available and providing recommendations on

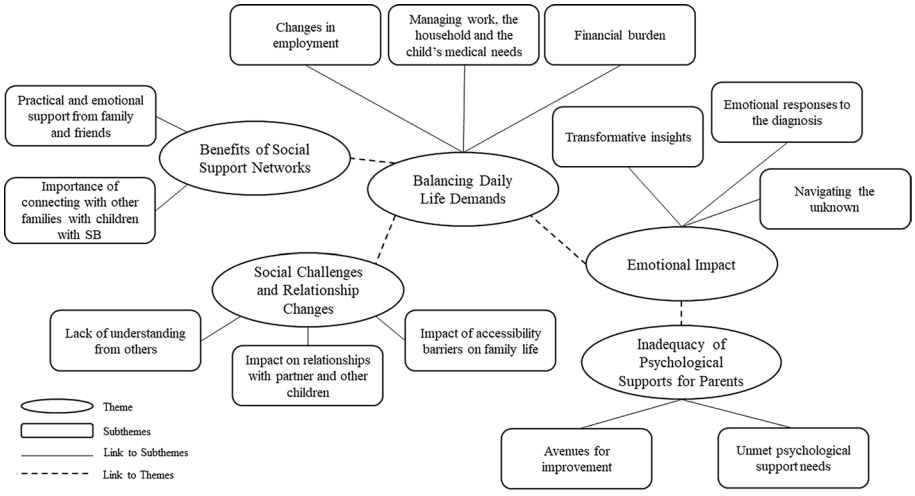

Fig. 1 Thematic map illustrating the relationship between the five themes

how to better support parents of children with SB. While we distinctly categorised the themes, they were also interrelated and associative. The relationships between the five themes are depicted in Fig. 1.

In the analysis which follows, ellipses have been inserted in square brackets where quotations have been contracted to remove irrelevant information. In cases where the context of a quote was lacking, contextual features or a potential meaning has been identified in square brackets. Quotations reflecting the range of issues that emerged were selected because they were typical of the insights that participants gave during interviews.

3.1 Balancing daily life demands

Participants reported that time spent engaging in the care and treatment of the child with SB, his or her dependency level, and the time spent attending medical appointments, in addition to typical carer responsibilities associated with child rearing, contributed to the difficulties in managing daily life demands. For example, Sarah (son, aged 11) disclosed:

> *"You just have so much more to do in your day. Do you know [...] doing washouts, he has to have that done every second day, and that's a good hour and a half of your evening when he comes home from school. And you're also trying to look after your other child doing homework and make dinner and do the stuff everybody has to do".*

Similarly, Nicole stated (daughter, aged 2):

> *"I don't have too many people minding [my daughter], I just haven't had like, it's either her dad or me. I know people can mind her, but there's a part of her medical care that's quite intrusive that we just wouldn't have everybody doing".*

Balancing these demands significantly influenced the careers of several participants. Participants reported that the trajectory of their professional lives had shifted significantly since the birth of their child with SB. Many participants transitioned to roles as full-time caregivers, as they found it challenging to sustain a career alongside the intensive responsibilities of caregiving. For instance, Ellen (son, aged 19) reported leaving her

previous employment to focus entirely on her child's needs: *"I would have been in management and when [my son's] care got quite complex […], I ended up taking voluntary redundancy because I was spending more time out of work than I was in work".*

Similarly, Monica (son, aged 15) reflected on the challenges she faced whilst balancing her career with her child's care needs:

> *"There had been a couple of times where he was in hospital and just the stress of trying to keep the job going and then be there for him, it was just too much. I just said I can't do that again, like I just can't be in that position where I can't just drop everything and be with him, but then still be torn to keeping, you know the job going".*

Participants reported that the impact on their careers frequently led to a noticeable reduction in their income. Many participants expressed that this financial strain was further compounded by medical expenses and the inadequacies of government support and funding. This was emphasised by Nicole (daughter, aged 2), who disclosed the significant financial burden experienced by her family: *"We've never actually been as financially worse off as we are now, but as she's getting older the cost is getting more. […] we have to pay a thousand euro for AFO's [ankle foot orthoses], because the [healthcare system] ones aren't fitting".*

3.2 Social challenges and relationship changes

Participants noted a considerable change in social dynamics and communication within and outside the immediate family, since having a child with SB. In terms of relationships outside of the family, participants consistently identified a lack of understanding from others regarding their child's condition and needs. Jessica (son, aged 7) reflected on how this lack of understanding affected her friendships: *"I lost a lot of friends really, because they didn't quite understand how much work goes into looking after a child with spina bifida, how much time and effort and what all is involved".*

Some participants noted that the insufficient understanding of their child's condition and care needs extended beyond their personal social circle. For instance, Cara (daughter, aged 3) identified a lack of awareness of SB within the community:

> *"There's really not enough awareness about spina bifida in the community […]. There are thousands of different pictures of spina bifida like, there's no one-size-fits-all, everyone's completely different. There are so many different levels, different things that spina bifida can affect in a person, and I feel like the general person wouldn't know about that unless you've experienced spina bifida".*

In terms of relationships within the immediate family, several participants mentioned a deterioration in their relationships with their partners, attributing this to a lack of quality time spent together and opposing views on the child's care. Amelia (daughter, aged 2) expressed:

> *"You become almost like business partners […]. People kind of get like that with kids anyway when they're young, but it's kind of compounded a bit then when you have this additional layer of…We can't just hand her off to family for an evening, you know, they can't just take her and let us get away".*

Moreover, participants identified additional impacts on the family system, particularly regarding the impact on the other siblings. Sarah (son, aged 11), for instance, reflected on the challenges her daughter faces due to the unpredictability of her son's condition: *"It's really hard for her you know, because I could bring him into hospital and not come back for 3 weeks and I think that's the part she finds really hard".*

Participants consistently reported of adjustments the other siblings made to accommodate the needs of the child with SB. For instance, Jessica (son, aged 7) described how her son's SB consistently takes precedence over the needs of her other child:

> *"I think for my oldest child, she feels left out a lot. She often says she wishes she was born with a disability [...],... as much as we try as a family to make those children feel important, my son's condition will always be at the forefront of everything".*

Participants also discussed the limitations imposed on their family outings and experiences due to accessibility concerns. Sarah (son, aged 11) acknowledged how these barriers to accessibility restrict her family in their activities: *"We can't just do what other families can do. We can't just have spontaneous days out. We can't just, we can't go to a beach. We can't. We have to always make sure everywhere is accessible".*

Similarly, Kate (son, aged 8) identified how these limitations often require careful consideration and the adjustment of plans to accommodate her child's needs: *"[You have to] look into everything and research things before you go anywhere to see if like, the surfaces or doors are wide enough, or if there's bathrooms".*

Despite these challenges, participants also identified positive changes within their family systems. Participants reported their families increased understanding and empathy towards others, in addition to an enhanced awareness of accessibility and disability. Several participants also reported that the challenges associated with their child's condition fostered a greater sense of unity and support within the family. Cara (daughter, aged 3) identified positive changes in her relationship with her immediate family:

> *"My immediate family, like, as is in my mom and dad, my brothers and sister, it brought us closer together because they kind of jumped in and they were on my side. They've delved into it with me, so it brought some of us closer together".*

3.3 Emotional impact

The initial discovery of their child's diagnosis had a profound impact on all participants, manifesting in emotions such as devastation, shock, worry, isolation, and grief. Amelia (daughter, aged 2) described the challenging early stages following the diagnosis: *"There was a long period of feeling kind of angry, feeling frustrated. It's almost like grieving in some ways".*

Similarly, Jessica (son, aged 7) recalled her initial response upon learning of her child's condition: *"It was shattering. Absolutely shattering. My whole body actually still goes like numb when I think about it."*

Some participants acknowledged that accepting the diagnosis is an ongoing, lifelong process that requires letting go of previous expectations about life. Amelia (daughter, aged 2) disclosed:

> *"I think the coming to terms with it is something that you have to do again every time you meet an obstacle [...]. So, the coming to terms thing I think is just lifelong.*

> *You have to come to terms with the next thing that she can or can't do, or you know the next adjustment that you have to make in your life […]. It's more letting go of what you thought was going to be".*

Participants reported concerns around the uncertainty and unpredictability regarding the course of their child's condition, and the trauma they endure as their child faces continuous medical interventions. At the initial diagnosis for instance, Monica (son, aged 15) recounted her worries regarding her child's prognosis: *"It's just not knowing what the outcome is going to be. Is he going to be able to walk? Or is he going to survive?".*

Participants identified having to constantly anticipate and prepare for potential medical emergencies or complications throughout the child's life. In this regard, Sarah (son, aged 11) noted:

> *"Everything is always so uncertain. Do you know, he definitely has a lifetime of surgeries ahead of him, but you never know what's coming. Especially when they have a shunt, you just never know what's coming […],… you live on tenterhooks all the time".*

Similarly, participants acknowledged how the unpredictable nature of medical interventions contributed to their stress. Jessica (son, aged 7) described her apprehension during her son's high-risk surgeries:

> *"I'm always on edge. But yeah, like coming up to the surgeries, I don't sleep, I don't eat. […]. I'm so busy going oh my God, what if this happens? We need to prepare for this. We need to do this. We need to have this ready. Yeah, it's a lot of like, stress".*

Louise (daughter, aged 5) similarly described her distress during these surgeries: *"All I do is cry, waiting until you get the call to say she's out of theatre".*

Participants also reported ongoing worries about their child's future, particularly regarding their independence and social acceptance. For instance, Cara (daughter, aged 3) expressed her concerns about her daughter's future: *"[I] worry about her being bullied and stuff, you know, kids can be mean. And if they spot anyone that's different, they pick on that, so […] I'd worry about that big time for [my daughter]".*

Participants reported a range of feelings, including guilt and distress, when comparing their child's capabilities with those of other children. Olivia (daughter, aged 16) expressed in this regard:

> *"[I'm always thinking of things she can't do, such as] going out to nightclubs, going to concerts, things like, that all her peers are able to do, I suppose and her siblings. So yeah, I find that very emotionally draining […]…it kind of hurts you, you know, it does [you] just get a little pain in your heart when you think about it".*

In light of these challenges, participants frequently expressed how their child's condition offered them a transformative perspective on life. Many remarked that everyday challenges seemed less significant in comparison to the ongoing hurdles their child faced. Rachel (daughter, aged 8) felt that: *"It really helps to bring into the proper proportionality any other issues or worries a person has in their life".*

Similarly, Sarah (son, aged 11) reflected on her child's own resilience:

> *"I just feel like he goes through so much […]. He's so strong for a child that has to go through so much. And it makes you just not sweat it over the small stuff anymore,*

and not to be worried about and giving out about silly stuff that you might have before".

3.4 Benefits of social support networks

Participants noted an overwhelming sense of support from their close social networks, including various forms of practical and emotional support. Olivia (daughter, aged 16) reflected on how her friends and family underwent medical training to provide practical support, and thereby alleviate caregiving responsibilities:

"My family are very good, very hands on. They did courses to help us with [my daughter's] tracheostomy and with administering antibiotics, and all of that. So, they were really, really, really hands on, and so were my friends in fairness. They all wanted to help, and they continue to do that".

Participants also disclosed the importance of having someone to confide in whilst managing their child's condition. Cara (daughter, aged 3) expressed appreciation for the emotional support provided by her social network: *"You really appreciate it when someone does help out […]. Even though they don't understand it, but they're making that effort".*

Participants also frequently identified the importance of connecting with other parents of children with SB. Patricia (daughter, aged 15) noted the benefits of sharing a mutual understanding of the challenges they face: *"Those of us who are already in the same trenches, you don't need to do any of the initial exploratory, explanatory, anything. You just get it, and that makes the world of difference".*

The benefits of the social support provided by these parents, particularly through the parent social media group, was consistently discussed by participants. Rachel (daughter, aged 8) reflected on how the group has helped her whilst navigating her child's diagnosis: *"In terms of helping me understand what it is like to be a mom with a child with spina bifida, it has been really, really helpful".*

Similarly, Cara (daughter, aged 3) acknowledged how the group has supported her in the past, and her ability to now support new parents in similar positions:

"Between us all, everyone has like a shared experience that will help somebody when they're struggling. Whenever I've come into difficulties, it's a great place that I always go to and I just vent and someone comes on and they're like, I've been through similar [..]. You can be the support for someone else. And that's so nice as well to feel like that, you're helping somebody from the experiences that you have had".

3.5 Inadequacy of psychological supports for parents

Participants confirmed that the impact of their child's condition on their psychological wellbeing was not acknowledged by medical professionals from the day they first received their child's diagnosis, to the present day. This was reflected in participants' perceptions in the lack of psychological support services available to parents of children with SB. Amelia (daughter, aged 2) recalled her personal experiences of isolation during pregnancy:

"I felt really, we were kind of just left to figure this out ourselves. You know, we were kind of told this is what it is […]. There was no chance to talk to anybody from, like, a counselling perspective. I think even if there had been a leaflet to say, you know,

> *this is the diagnosis, or an information pack and it had 'phone this number' if you want to talk to somebody if you have any questions. It just kind of felt like we were left to Google everything […]. I felt like we were kind of let down there where, you know, we're cared for from a physical perspective, but that actual helping us get through our heads and help us process, that wasn't there at all, because seriously like, it is life changing stuff".*

Similarly, Jessica (son, aged 7) reflected on the lack of acknowledgement by healthcare professionals during one of her son's hospital visits:

> *"[My son] was rushed off to hospital. I was sleeping on a very uncomfortable chair for four days, no sleep, didn't get a chance to shower or even wash my face, anything. And I felt like everyone was going, oh, he's fine. And no one was going are you ok, like, that was traumatic, are you ok?".*

Repeatedly, participants identified the need to improve psychological supports for parents of children with SB. Cara (daughter, aged 3) recounted the following in this regard:

> *"We're going through it all with [our children] as well, it's not just the kids. And if we're helped along the journey, it's only going to help the kid's outcome later in life. So, it's going to have a huge knock-on effect that like everyone's taking care of each other".*

Participants stated that both support groups and individual counselling would be beneficial. For instance, Patrica (daughter, aged 15) highlighted her preference for individual counselling: *"Individual opportunities to offload to a therapist or something would be really, really beneficial for so many of us".*

Whilst on the other hand, Monica (son, aged 15) felt that support groups would be most beneficial: *"Meeting with other parents in similar situations in a group is good […]. I think it would be beneficial, especially when your child is much younger, and you really have no idea what you're dealing with".*

4 Discussion

To the best of our knowledge, this is the first study that qualitatively explores the psychosocial impact of having a child with SB. Moreover, whilst there is a small amount of research pertaining to the psychosocial impact of having a child with SB, there is a lack of literature qualitatively assessing the subjective experiences of these parents, as illustrated by Rofail et al. [60]. The findings indicate that these parents are impacted in both positive and negative ways by their child's condition. We identified five themes: balancing daily life demands, social challenges and relationship changes, emotional impact, benefits of social support networks and inadequacy of psychological supports for parents. As such, research question (i) was addressed through the themes of daily life demands, social challenges and relationship changes, and emotional impact, by highlighting the psychosocial impacts experienced by parents of children with SB. Research questions (ii) and (iii) were addressed by the remaining two themes, benefits of social support networks and inadequacy of psychological supports for parents, which highlight the various supports available and recommendations on how to better support parents of children with SB.

A significant finding is the challenges participants face in balancing typical carer responsibilities associated with child rearing, in addition to disability-related responsibilities, such as time spent attending medical appointments and the management of their child's medical regimen. Participants consistently identified the significant amount of time spent engaging in daily care, such as dressing, bathing, catheterising, or completing bowel washouts for their child. This is reflected in the earlier findings of Havermans and Eiser [26], who found that in comparison to parents with able-bodied children, caregivers of children with SB spent more time with their child, particularly due to SB-related care needs such as incontinence and lack of mobility. Although this research was published in 1991, our study found that these caregiver responsibilities placed on parents of children with SB, persist to this day.

Participants reported that balancing these daily life demands significantly impacted their careers. As such, the trajectory of their professional lives had shifted significantly since the birth of their child with SB, with several participants transitioning to the role of full-time caregivers. Aksenov et al. [1] also found that caregivers of children with SB reported making work adjustments due to their child's condition, which ranged from shifting their work schedule, to quitting work altogether to care for their child. Similarly, Cavalari et al. [10] reported that in their study, 81% of parents of children with myelomeningocele did not have paid work and were dedicated exclusively to their child's care.

Parents acknowledged that these changes in employment exacerbated their financial stress, in addition to the lack of government support received. This was further compounded by medical expenses such as private therapies and mobility equipment, travel costs such as parking, and costs related to home adaptations to improve accessibility. Similar expenses have been reported by parents of children with SB located in the United States [1].

Another important finding is that participants noted a considerable change in social dynamics and communication within and outside the immediate family, since having a child with SB. Regarding relationships outside of the family, the lack of awareness and understanding about SB strongly featured in the parents' accounts. Participants identified a lack of understanding about SB among their family members, friends, and the wider community. In particular, participants reported a lack of understanding from friends regarding their child's condition and needs, which often led to feelings of isolation. Previous research has reported that parents of children with cerebral palsy noted a lack of understanding by relatives and other community members of their difficulties, and little or no acknowledgement of the challenges faced [2].

In terms of relationships within the family, participants identified several aspects of family functioning that were particularly salient, including marital relationships and sibling adjustment. Several participants noted a deterioration in their relationships with their partners, attributing this to a lack of quality time spent together and opposing views on the child's care. This is also reflected in the findings of Loebig [43], who found that parents of children with SB reported tensions or strains within their marital relationships, due to their child's condition.

Participants frequently identified the impact of SB on the other siblings. Several parents reported that due to the amount of time spent with the child with SB, less time was spent with any other children they might have. Participants felt that their able-bodied children were impacted as a result of parental absence due to hospitalisations, the

unpredictability of the child's condition, having to make adjustments to accommodate the needs of the child with SB, and limitations on their family outings and experiences due to accessibility concerns. This placed considerable strain on the parents, as they navigated balancing the needs of their child with SB and the needs of their other children, with many participants reporting feelings of guilt. These findings support the existing body of research on the impact on siblings of children with chronic illness (e.g., [27]).

Despite these impacts and the challenges associated with rearing a child with SB, several participants also noted positive changes within their family systems. Participants reported that their entire family, including the siblings, gained compassion, awareness, and empathy for others. These findings have been reported in previous research, in which siblings of children with SB identified various positive effects, such as increased empathy for their sibling and a greater appreciation of their own physical abilities [30]. Moreover, participants reported that the challenges associated with their child's condition fostered a greater sense of unity and support within the family. This is similar to the findings of Bellin and Rice [4], in which siblings reported that the shared SB experience created family bonds that seemed stronger than those of other families. Furthermore, participants frequently expressed how their child's condition offered them a transformative perspective on life. Many participants remarked that everyday challenges seemed less significant in comparison to the ongoing hurdles their child faced, which was similarly reported by parents of children with children with SB in a study by Holmbeck and Devine [30]. Previous research on parents of children with rare diseases has described a revitalised world view including a sense of gratefulness and a deeper understanding of their child, themselves, and others [49].

Another key finding is the profound emotional impact that the child's SB had on all participants. Participants reflected on their personal experiences during the initial diagnosis, commonly recalling feelings of shock at the time when they learned of their baby's diagnosis. Additional responses reported by participants during this period included several emotions, such as devastation, worry, guilt, and grief. Such findings consolidate previous research on parents' experiences of prenatal diagnosis of SB (e.g., [13]).

Like parents of children with other chronic conditions (e.g., [29, 37]), uncertainty was a constant part of daily life and dominated parents' accounts of living with a child with SB. This uncertainty encompassed a broad spectrum of concerns, including initial diagnostic uncertainty, anticipation of potential medical emergencies or complications, and ongoing concerns about their child's future, particularly regarding their independence and social acceptance. Smith et al. [67] found that parents of children with hydrocephalus reported similar uncertainties, such as the unpredictable nature of shunt complications, risks associated with surgeries and uncertainty about the child's ability to live independently. Participants also reported that the uncertainty surrounding their child's diagnosis can persist or re-emerge at challenging transition points in their child's life. Thus, in line with previous research, these findings suggest that any resolution of parental uncertainty may only be partial or transient [17].

Another key finding is the importance of social support networks for these parents. Participants emphasised various sources of support, such as their partner, family, and friends. These support systems provided practical support to alleviate caregiving demands, opportunities to share childcare responsibilities, and an outlet to share their worries and concerns. Pinquart [55] also reported that higher levels of perceived social

support were associated with lower levels of parental stress in caregivers of children with chronic physical conditions. Thus, there is a clear importance in having a social support network for parents of children with SB.

Moreover, participants consistently acknowledged the importance of connecting with other parents of children with SB. This form of peer support fostered a sense of belonging, and reduced feelings of isolation and loneliness. Additionally, participants utilised this support network to exchange practical information, and many parents described learning from the expertise and experience of other parents. Peer networks help to reduce psychological distress and feelings of isolation, enhance coping skills, and provide altruistic benefit in supporting others (e.g., [8]).

Participants identified a lack of acknowledgement by medical professionals for the impact their child's condition had on their psychological wellbeing, from the day they first received their child's diagnosis. This was reflected in participants' perceptions of the lack of psychological support services available to parents of children with SB. This is consistent with previous research on parents of children with rare diseases, which found that despite parents feeling emotionally distressed and in a state of shock, few parents were offered psychological support from mental health professionals, particularly around the time of diagnosis, when need was greatest [51]. Robertson et al. [59] found that parents of children with serious chronic conditions reported a greater need for mental health support. As such, there is a body of literature highlighting the clear lack of professional support for parents of children with chronic conditions, however, the present study is the first, to our knowledge, to identify the lack of services for parents in the instance of SB.

4.1 Implications

In terms of clinical implications, the findings underscore the critical need for the improvement of psychological support services tailored for parents of children with SB in Ireland. It is important to acknowledge that these findings are limited to the context of the Irish healthcare system and may not be directly applicable to healthcare services in other countries. Firstly, the findings demonstrate that there is a need for better signposting of supportive resources for parents of children with SB, particularly at the point of diagnosis. Secondly, participants highlighted that existing support structures are insufficient and inadequate. Thus, where supports are available and where services do exist for these parents, there is a need to address the challenges faced specifically by parents of children with SB, such as financial challenges, psychological challenges, and caregiver burden. Several participants suggested that interventions that facilitate peer support may be particularly beneficial at addressing these issues, which has been supported by previous research (e.g., [40, 65]). Finally, it is imperative that healthcare professionals acknowledge and address the profound impact that SB has on caregivers. Recent studies emphasise that discussions about parental mental health should occur early and often as part of routine care for paediatric illness (e.g., [6, 35, 53]). Facilitating discussions around parents' mental health by actively inquiring about how parents are coping, can facilitate early identification of mental health challenges warranting intervention [21, 53]. When necessary, referrals to hospital and community based psychosocial supports may further promote parents' confidence that their needs can be met through the healthcare system. Ultimately, this would have beneficial effects for the child with SB and their caregivers [80].

Regarding future avenues for research, given the lack of literature qualitatively assessing the subjective experiences of parents of children with SB, there is a clear need for further research in this area. Moreover, given that parents emphasised the significant impact of SB on the able-bodied sibling, future research qualitatively assessing the experience of siblings of those with SB is warranted. Finally, future research with neuropsychology professionals would be beneficial to develop targeted interventions for parents of SB to support their unique psychosocial needs.

4.2 Strengths and limitations

To the best of our knowledge, this is the first study that qualitatively explores the psychosocial impact of having a child with SB. Unlike quantitative studies that are limited by the scope of impacts covered in the outcome measures used, this qualitative study enabled parents to share their unique experiences associated with caring for their child with SB. However, this study is not without limitations. The research was conducted online, with all interviews taking place remotely over Zoom. This approach may have restricted the researcher's ability to capture non-verbal cues and establish the same level of rapport that is established in face-to-face interviews. Despite this, interviews were rich in data, which suggests that the online nature of the interviews did not impact the quality of the data. A significant limitation in the present study is that one author was primarily responsible for the data analysis, which may have introduced interpretive bias, and the analytical depth derived from multiple perspectives. Furthermore, this research explored the experience of parents of children with SB residing in Ireland, and therefore, these findings may have limited generalisability to other populations. Lastly, as with many psychosocial research studies (e.g., [59]), there was an under-representation of fathers. Whilst this corroborates the literature documenting that mothers continue to be the primary caregivers (e.g., [10, 44]), we recommend that this study be replicated using father figures and caregivers from gender minority groups for more representativeness.

5 Conclusion

In conclusion, the present study identified five themes relating to the psychosocial impact of having a child with SB: balancing daily life demands, social challenges and relationship changes, emotional impact, benefits of social support networks and inadequacy of psychological supports for parents. These findings highlight the significant impact that having a child with SB has on parents, yet participants felt that the impact of their child's condition on their psychological wellbeing was not acknowledged by medical professionals. Furthermore, the study highlights the evident positive and negative impacts the child's diagnosis of SB has on the parent and their families. Positive impacts reported include a greater sense of unity and support within the family and a transformative perspective on life, while negative impacts include the caregiving demands associated with disability-related responsibilities and the uncertainty and unpredictability regarding the course of their child's condition. Participants reported an overwhelming sense of support from their close social networks, however, there was a clear lack of professional psychological support available to these parents from the day of diagnosis to the present day. Thus, the findings underscore the critical need for the improvement of psychological support services tailored for parents of children with SB.

Acknowledgements
With thanks to all our participants for partaking in this study.

Author contribution
Katie O'Connor: Conceptualization, Methodology, Data curation, Data analysis and interpretation, Original manuscript preparation, Writing—review and editing. David Hevey: Conceptualization, Data curation and design, Supervision, Manuscript review and editing.

Funding
This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Data availability
The data that support the findings of this study are not openly available due to reasons of sensitivity and are available from the corresponding author upon reasonable request.

Declarations

Ethical approval and consent to participate
This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Psychology Research Ethics Committee (REC), Trinity College Dublin (SPREC012024-18). Informed consent for participation was obtained from all participants prior to participation in this research.

Consent for publication
Informed consent regarding the potential publication of pseudo-anonymised data in an academic journal or conference was obtained from participants prior to participation in this research.

Competing interests
The authors declare no competing interests.

Received: 2 January 2025 / Accepted: 16 July 2025
Published online: 28 August 2025

References

1. Aksenov LI, Fairchild RJ, Hobbs KT, Tejwani R, Wiener JS, Routh JC. Financial toxicity among individuals with spina bifida and their families: a qualitative study and conceptual model. J Pediatr Urol. 2022;18(3):290.e1-290.e8. https://doi.org/10.1016/j.jpurol.2022.03.002.
2. Alaee N, Shahboulaghi FM, Khankeh H, Mohammad Khan Kermanshahi S. Psychosocial challenges for parents of children with cerebral palsy: a qualitative study. J Child Fam Stud. 2015;24(7):2147–54. https://doi.org/10.1007/s10826-014-0016-3.
3. Barreto TM, Bento MN, Barreto TM, Jagersbacher JG, Jones NS, Lucena R, Bandeira ID. Prevalence of depression, anxiety, and substance-related disorders in parents of children with cerebral palsy: a systematic review. Dev Med Child Neurol. 2020;62(2):163–8.
4. Bellin MH, Rice KM. Individual, family, and peer factors associated with the quality of sibling relationships in families of youths with spina bifida. J Fam Psychol. 2009;23(1):39–47. https://doi.org/10.1037/a0014381.
5. Betz CL, Smith KA, Kysh L, Roland M, Van Speybroeck A, Castillo P, Liley F, Hudson S, Mannino JE. Psychosocial outcomes for adults with spina bifida: a scoping review protocol. JBI Evid Synthesis. 2020;18(5):1135–43.
6. Boat TF, Filigno S, Amin RS. Wellness for families of children with chronic health disorders. JAMA Pediatr. 2017;171(9):825. https://doi.org/10.1001/jamapediatrics.2017.1682.
7. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. https://doi.org/10.1191/1478088706qp063oa.
8. Bray L, Carter B, Sanders C, Blake L, Keegan K. Parent-to-parent peer support for parents of children with a disability: a mixed method study. Patient Educ Couns. 2017;100(8):1537–43.
9. Brea CM, Munakomi S. Spina Bifida. In StatPearls. 2024. StatPearls Publishing. http://www.ncbi.nlm.nih.gov/books/NBK559265/.
10. Cavalari KN, Hamamoto Filho PT, Caldeira SM, Nunes HRDC, Lima FMA, De Avila MAG. Functional independence of children with myelomeningocele: is it associated with the informal caregivers' burden? J Pediatr Nurs. 2017;36:232–5. https://doi.org/10.1016/j.pedn.2017.07.005.
11. Cavalheiro S, Da Costa MDS, Barbosa MM, Dastoli PA, Mendonça JN, Cavalheiro D, Moron AF. Hydrocephalus in myelomeningocele. Childs Nerv Syst. 2021;37(11):3407–15. https://doi.org/10.1007/s00381-021-05333-2.
12. CDC. Global NTD Prevention|CDC. 2022. Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/folicacid/global-ntd-prevention.html.
13. Chaplin J, Schweitzer R, Perkoulidis S. Experiences of prenatal diagnosis of spina bifida or hydrocephalus in parents who decide to continue with their pregnancy. J Genet Couns. 2005;14(2):151–62. https://doi.org/10.1007/s10897-005-0488-9.
14. Clarke V, Braun V. Successful qualitative research: a practical guide for beginners. Successful Qual Res. 2016;1–400.
15. Copp AJ, Greene NDE. Neural tube defects—disorders of neurulation and related embryonic processes. WIREs Dev Biol. 2013;2(2):213–27. https://doi.org/10.1002/wdev.71.
16. Cousino MK, Hazen RA. Parenting stress among caregivers of children with chronic illness: a systematic review. J Pediatr Psychol. 2013;38(8):809–28.
17. Coyne I, Malone H, Chubb E, While AE. Transition from paediatric to adult healthcare for young people with cystic fibrosis: Parents' information needs. J Child Health Care. 2018;22(4):646–57. https://doi.org/10.1177/1367493518768448.
18. Dikeç G, Türk E, Yüksel E, Çelebi K, Özdemir M. Experiences of hearing parents of children with hearing loss: a qualitative study. Children. 2023;10(7): 1129. https://doi.org/10.3390/children10071129.

19. Ergenekon AP, Gümüş Z, Yegit CY, Cenk M, Gulieva A, Kalyoncu M, Selcuk M, Karabulut S, Ozturk G, Eralp EE, Unver O, Karadag B, Gokdemir Y. Depression, anxiety, and sleep quality of caregivers of children with spinal muscular atrophy. Pediatr Pulmonol. 2023;58(6):1697–702. https://doi.org/10.1002/ppul.26379.
20. Espinal RR, Msall ME. Developmental disabilities: physical. In: Encyclopedia of infant and early childhood development. Amsterdam: Elsevier; 2008. p. 382–94. https://doi.org/10.1016/B978-012370877-9.00050-5.
21. Franklin MK, Karpyn A, Christofferson J, McWhorter LG, Demianczyk C, Brosig AL, Jackson CA, Lihn E, Zyblewski SC, Kazak SEA, Sood E. Barriers and facilitators to discussing parent mental health within child health care: perspectives of parents raising a child with congenital heart disease. J Child Health Care. 2023;27(3):360–73. https://doi.org/10.1177/13674935211058010.
22. Giza CC, Sankar R. Spina Bifida (SB). Chronic complex diseases of childhood: a practical guide for clinicians. 2011;460.
23. Golfenshtein N, Srulovici E, Medoff-Cooper B. Investigating parenting stress across pediatric health conditions-a systematic review. Compr Child Adolesc Nurs. 2016;39(1):41–79.
24. Guest G, Bunce A, Johnson L. How many interviews are enough? An experiment with data saturation and variability. Field Methods. 2006;18(1):59–82.
25. Hatzmann J, Maurice-Stam H, Heymans HS, Grootenhuis MA. A predictive model of health related quality of life of parents of chronically ill children: the importance of care-dependency of their child and their support system. Health Qual Life Outcomes. 2009;7(1):1–9.
26. Havermans T, Eiser C. Mothers' perceptions of parenting a child with spina bifida. Child Care Health Dev. 1991;17(4):259–73.
27. Havill N, Fleming LK, Knafl K. Well siblings of children with chronic illness: a synthesis research study. Res Nurs Health. 2019;42(5):334–48. https://doi.org/10.1002/nur.21978.
28. Heiman T. Parents of children with disabilities: resilience, coping, and future expectations. J Dev Phys Disabil. 2002;14:159–71.
29. Hinton D, Kirk S. Living with uncertainty and hope: a qualitative study exploring parents' experiences of living with childhood multiple sclerosis. Chronic Illn. 2017;13(2):88–99. https://doi.org/10.1177/1742395316664959.
30. Holmbeck GN, Devine KA. Psychosocial and family functioning in spina bifida. Dev Disabil Res Rev. 2010;16(1):40–6.
31. ICBDSR. The Centre of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR). Annual Report 2014. The Centre of the International Clearinghouse for Birth Defects Surveillance and Research. 2014.
32. Jackson AC, Higgins RO, Frydenberg E, Liang RP-T, Murphy BM. Parent's perspectives on how they cope with the impact on their family of a child with heart disease. J Pediatr Nurs. 2018;40:e9–17.
33. Kancherla V. Neural tube defects: a review of global prevalence, causes, and primary prevention. Childs Nerv Syst. 2023;39(7):1703–10. https://doi.org/10.1007/s00381-023-05910-7.
34. Kaplowitz MD. Statistical analysis of sensitive topics in group and individual interviews. Qual Quant. 2000;34(4):419–31. https://doi.org/10.1023/A:1004844425448.
35. Kasparian NA, Kan JM, Sood E, Wray J, Pincus HA, Newburger JW. Mental health care for parents of babies with congenital heart disease during intensive care unit admission: systematic review and statement of best practice. Early Hum Dev. 2019;139: 104837. https://doi.org/10.1016/j.earlhumdev.2019.104837.
36. Kazak AE, Holmbeck GN, Gorey-Ferguson L, Hudson T, Sefeldt T, Shapera W, Turner T, Uhler J. Maternal, paternal, and marital functioning in families of preadolescents with Spina Bifida. J Pediatr Psychol. 1997;22(2):167–81. https://doi.org/10.1093/jpepsy/22.2.167.
37. Kerr AM, Haas SM. Parental uncertainty in illness: Managing uncertainty surrounding an" orphan" illness. J Pediatr Nurs. 2014;29(5):393–400.
38. Khanna AK, Prabhakaran A, Patel P, Ganjiwale JD, Nimbalkar SM. Social, psychological and financial burden on caregivers of children with chronic illness: a cross-sectional study. Indian J Pediatr. 2015;82(11):1006–11. https://doi.org/10.1007/s12098-015-1762-y.
39. King, D., O'Rourke, N., & DeLongis, A. (2014). Social media recruitment and online data collection: A beginner's guide and best practices for accessing low-prevalence and hard-to-reach populations. Canadian Psychology, 55(4):240–249.
40. Lancaster K, Bhopti A, Kern ML, Taylor R, Janson A, Harding K. Effectiveness of peer support programmes for improving well-being and quality of life in parents/carers of children with disability or chronic illness: a systematic review. Child Care Health Dev. 2023;49(3):485–96. https://doi.org/10.1111/cch.13063.
41. Lee S, Yoo J-S, Yoo I-Y. Parenting stress in mothers of children with congenital heart disease. Asian Nurs Res. 2007;1(2):116–24. https://doi.org/10.1016/S1976-1317(08)60014-6.
42. Leiter V, Krauss MW, Anderson B, Wells N. The consequences of caring: effects of mothering a child with special needs. J Fam Issues. 2004;25(3):379–403.
43. Loebig M. Mothers' assessments of the impact of children with spina bifida on the family. Matern Child Nurs J. 1990;19(3):251–64.
44. Macedo EC, Silva LRD, Paiva MS, Ramos MNP. Burden and quality of life of mothers of children and adolescents with chronic illnesses: an integrative review. Rev Latino-Am Enfermagem. 2015;23(4):769–77. https://doi.org/10.1590/0104-1169.0196.2613.
45. Martinez H, Benavides-Lara A, Arynchyna-Smith A, Ghotme KA, Arabi M, Arynchyn A. Global strategies for the prevention of neural tube defects through the improvement of folate status in women of reproductive age. Childs Nerv Syst. 2023;39(7):1719–36. https://doi.org/10.1007/s00381-023-05913-4.
46. McDonnell RJ, Delany V, O'Mahony MT, Lynch C, McKeating A, Monteith C, Turner MJ. An audit of neural tube defects in the Republic Of Ireland for 2012–2015. 2018.
47. McDonnell R, Delany V, O'Mahony M, Mullaney C, Lee B, Turner M. Neural tube defects in the Republic of Ireland in 2009–11. J Public Health. 2015;37(1):57–63.
48. Medway M, Tong A, Craig JC, Kim S, Mackie F, McTaggart S, Walker A, Wong G. Parental perspectives on the financial impact of caring for a child with CKD. Am J Kidney Dis. 2015;65(3):384–93.
49. Ngo, D., Aouad, P., Goodison-Farnsworth, M., Gorrie, A., Kenmuir, T., & Jaaniste, T. (2023). Impacts of paediatric chronic pain on parents: A qualitative study. Child: Care, Health and Development, 49(4):645–656. https://doi.org/10.1111/cch.13079
50. Nimbalkar S, Raithatha S, Shah R, Panchal DA. A qualitative study of psychosocial problems among parents of children with cerebral palsy attending two tertiary care hospitals in Western India. ISRN Family Medicine. 2014;2014:1–6. https://doi.org/10.1155/2014/769619.

51. Pelentsov LJ, Laws TA, Esterman AJ. The supportive care needs of parents caring for a child with a rare disease: a scoping review. Disabil Health J. 2015;8(4):475–91. https://doi.org/10.1016/j.dhjo.2015.03.009.
52. Phillips LA, Burton JM, Evans SH. Spina bifida management. Curr Probl Pediatr Adolesc Health Care. 2017;47(7):173–7.
53. Pickles DM, Lihn SL, Boat TF, Lannon C. A roadmap to emotional health for children and families with chronic pediatric conditions. Pediatrics. 2020;145(2): e20191324. https://doi.org/10.1542/peds.2019-1324.
54. Pike M. Disorders of the spinal cord in children. Mac Keith Press. 2013.
55. Pinquart M. Parenting stress in caregivers of children with chronic physical condition—a meta-analysis. Stress Health. 2018;34(2):197–207. https://doi.org/10.1002/smi.2780.
56. Pope C. Qualitative research in health care: analysing qualitative data. BMJ. 2000;320(7227):114–6. https://doi.org/10.1136/bmj.320.7227.114.
57. Richterová R, Kolarovszki B, Opšenák R. Management of pediatric patients with spina bifida. In: Kolarovszki B, Messina R, Blè V, Editors. Spina bifida and craniosynostosis—new perspectives and clinical applications. IntechOpen. 2021. https://doi.org/10.5772/intechopen.97237.
58. Ridosh MM, Sawin KJ, Roux G, Brei TJ. Quality of life in adolescents and young adults with and without spina bifida: an exploratory analysis. J Pediatr Nurs. 2019;49:10–7.
59. Robertson EG, Kelada L, Ilin R, Palmer EE, Bye A, Jaffe A, Kennedy SE, Ooi CY, Drew D, Wakefield CE. Psychological wellbeing among parents of a child living with a serious chronic illness: a cross-sectional survey study. J Child Health Care. 2024;13674935241238485. https://doi.org/10.1177/13674935241238485.
60. Rofail D, Maguire L, Heelis R, Colligs A, Lindemann M, Abetz L. The impact of spina bifida on caregivers. Neurol Ther. 2012;1(1):4. https://doi.org/10.1007/s40120-012-0004-8.
61. Rose, B. M., & Holmbeck, G. N. (2007). Attention and Executive Functions in Adolescents with Spina Bifida. Journal of Pediatric Psychology, 32(8):983–994. https://doi.org/10.1093/jpepsy/jsm042
62. Rossi A, Biancheri R, Cama A, Piatelli G, Ravegnani M, Tortori-Donati P. Imaging in spine and spinal cord malformations. Eur J Radiol. 2004;50(2):177–200.
63. Sandler AD. Children with spina bifida: key clinical issues. Pediatr Clin North Am. 2010;57(4):879–92. https://doi.org/10.1016/j.pcl.2010.07.009.
64. Santamaria F, Cuzzocrea F, Gugliandolo MC, Larcan R. Marital satisfaction and attribution style in parents of children with autism spectrum disorder, down syndrome and non-disabled children. Life Span and Disability. 2012;15(1):19–37.
65. Shilling V, Morris C, Thompson-Coon J, Ukoumunne O, Rogers M, Logan S. Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. Dev Med Child Neurol. 2013;55(7):602–9. https://doi.org/10.1111/dmcn.12091.
66. Smith J, Cheater F, Bekker H. Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. Health Expect. 2015;18(4):452–74. https://doi.org/10.1111/hex.12040.
67. Smith J, Cheater F, Bekker H. Parents' experiences of living with a child with hydrocephalus: a cross-sectional interview-based study. Health Expect. 2015;18(5):1709–20. https://doi.org/10.1111/hex.12164.
68. Smith S, Tallon M, Clark C, Jones L, Mörelius E. "you never exhale fully because you're not sure what's Next": parents' experiences of stress caring for children with chronic conditions. Front Pediatr. 2022;10: 902655. https://doi.org/10.3389/fped.2022.902655.
69. Stallings, E. B., Isenburg, J. L., Rutkowski, R. E., Kirby, R. S., Nembhard, W. N., Sandidge, T., Villavicencio, S., Nguyen, H. H., McMahon, D. M., Nestoridi, E., Pabst, L. J., & for the National Birth Defects Prevention Network. (2024). National population-based estimates for major birth defects, 2016–2020. Birth Defects Research, 116(1):e2301 https://doi.org/10.1002/bdr2.2301
70. Stern A, Amaral S, Bechtel Driscoll CF, Psihogios AM, Stiles-Shields C, Zebracki K, Holmbeck GN. Spina bifida. In: Adherence and self-management in pediatric populations. Amsterdam: Elsevier; 2020. p. 235–61. https://doi.org/10.1016/B978-0-12-816000-8.00010-4.
71. Szymanski KM, Cain MP, Whittam B, Kaefer M, Rink RC, Misseri R. Incontinence affects health-related quality of life in children and adolescents with spina bifida. J Pediatr Urol. 2018;14(3):279.e1–279.e8. https://doi.org/10.1016/j.jpurol.2018.02.021.
72. Taylor S, McAvoy J. Researching the psychosocial: an introduction. Qual Res Psychol. 2015;12(1):1–7. https://doi.org/10.1080/14780887.2014.958043.
73. Thompson DN. Spinal dysraphic anomalies; classification, presentation and management. Paediatr Child Health. 2014;24(10):431–8.
74. Ulual P, Ozer V, Özpınar G, Alataş I, Çetiner R, Güçlü O. A comparison about the depression, anxiety, and despair levels of the parents' of healthy children and children with Spina bifida disease. Eur Psychiatry. 2023;66(S1):S587–8. https://doi.org/10.1192/j.eurpsy.2023.1228.
75. Vermaes IPR, Gerris JRM, Mullaart RA, Geerdink N, Janssens JMAM. PMTS and stress response sequences in parents of children with spina bifida. Eur J Paediatr Neurol. 2008;12(6):446–54. https://doi.org/10.1016/j.ejpn.2007.11.002.
76. Ware, A. L., Kulesz, P. A., Juranek, J., Cirino, P. T., & Fletcher, J. M. (2017). Cognitive control and associated neural correlates in adults with spina bifida myelomeningocele. Neuropsychology, 31(4):411–423. https://doi.org/10.1037/neu0000350
77. Woodgate RL, Edwards M, Ripat JD, Borton B, Rempel G. Intense parenting: a qualitative study detailing the experiences of parenting children with complex care needs. BMC Pediatr. 2015;15(1): 197. https://doi.org/10.1186/s12887-015-0514-5.
78. Young S, Shakespeare-Finch J, Obst P. Raising a child with a disability: a one-year qualitative investigation of parent distress and personal growth. Disabil Soc. 2020;35(4):629–53. https://doi.org/10.1080/09687599.2019.1649637.
79. Zahl E, Dale SS, Fjermestad KW, Vatne TM. Parenting a child with a disability: fathers' perceptions of the couple relationship. J Soc Pers Relat. 2024;41(9):2548–68. https://doi.org/10.1177/02654075241248387.
80. Zipitis CS, Paschalides C. Caring for a child with spina bifida: understanding the child and carer. J Child Health Care. 2003;7(2):101–12.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.